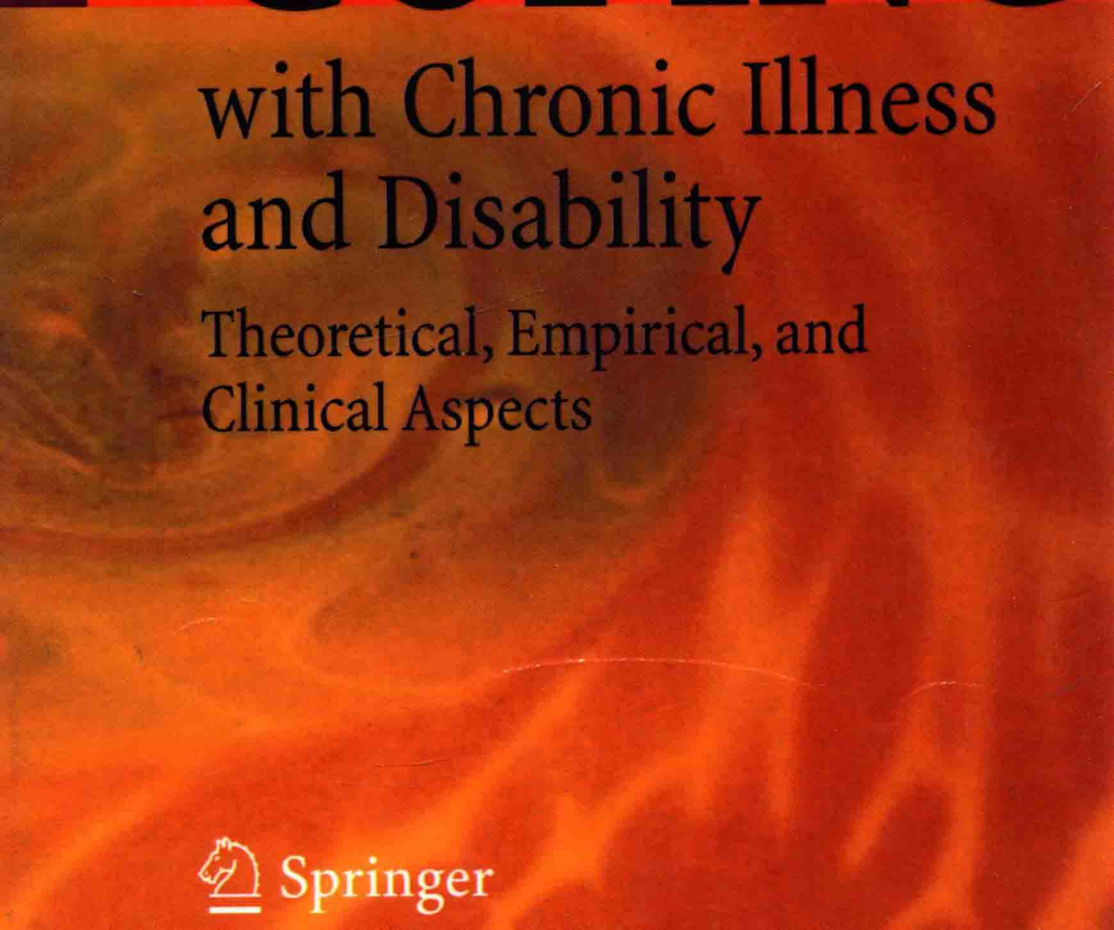

Erin Martz
Hanoch Livneh
*Editors*

# COPING

## with Chronic Illness and Disability

### Theoretical, Empirical, and Clinical Aspects

Springer

# Coping with Chronic Illness and Disability

## Theoretical, Empirical, and Clinical Aspects

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# Coping with Chronic Illness and Disability

# *The Uninvited Guest*

It's there every
day, every hour,
every minute,
begging you for attention
like a hungry child,
demanding your thoughts
like an expectant teacher,
draining your energy
like an air-conditioner
on a monsoon day.
It's permanently there,
like a deep scar, a tattoo,
like a traumatic memory,
like the stars in a Hawaiian sky,
like the soft, clingy Bahraini sands,
like the bubbling Arkansas hot springs,
like the friend who forgives your mistakes.
Disability permeates the wrinkles of our lives
and can blossom into new growth,
as we shed the shame and pain
that usher in its arrival.

– Erin Martz

# Foreword

A volume that deals in depth with a coping approach to chronic illness and disability (CID), based on theory, research and clinical aspects, holds much promise to improve the lives of people directly affected. But such a volume, with its many contributors and wide scope, may also harbor minefields along the way that undermine the actual individuals who are trying to cope with their condition. The reader, therefore, needs carefully to think through the implications of the particular content of each chapter, in order to detect and thereby avoid prejudicial consequences. This foreword concerns flawed human perception and corrective perspectives, not statistical issues.

To alert the reader, a variety of factors commonly involved in how we, as humans, perceive people, are briefly described – factors that unconsciously interfere with the promise of coping well or even adequately with adversity. This is followed by a set of counteracting strategies. An elaboration of the concepts involved, together with supporting research, may be found in Wright (1983, 1991).

One interfering factor is the **Fundamental Negative Bias**. It states that when something stands out as negative, and when the context lacks positives to control the negative spread, the mind goes negative; i.e., the train of thought on the part of the perceiver, be it oneself or another person, is forced onto a negative track of inferences concerning causes and effects of the troubling situation. Coping possibilities have then to break through the grip of overwhelming negatives.

The **Potency of Negatives** is another powerful force reinforcing the negative thrust. It refers to the tendency to give more weight to negatives than to positives. This tendency steers the perceiver away from coping possibilities which, after all, require taking advantage of whatever is positive and potentially helpful.

A third factor is known as the **Just World Phenomenon** (Lerner, 1980). It refers to the belief that suffering and punishments, like joys and rewards, should be deserved. By aligning the existing reality with what is right and ought to be, the danger is that the mind unconsciously slips into blaming the victim, be it oneself or someone else, for the distress – a force that clearly has to be reckoned with in encouraging a coping approach to difficulties.

Still another formidable factor obscuring coping possibilities is the strong tendency toward the **Eclipse of the Environment** when the target of concern is a person. Essentially, this is a figure-ground problem. To recognize that the *realities of the environment* need to be included in assessment and rehabilitation procedures would appear to be axiomatic, because behavior is always a function of both the person and the environment (Lewin, 1935). And yet, because it is the person who comes in for treatment, not the environment, the environment remains ignored in the murky background. Special effort is thus required to bring the un-illuminated environment into focus.

Fortunately, there are a number of perspectives that serve to counter the factors that interfere with the best coping efforts. One important perspective is that of the **Insider vs. Outsider** (Dembo, 1964). The insider is the person directly experiencing CID, whereas the outsider is the observer or evaluator of the condition. Frequently, it is the insider who is more attuned to the immediate environment, in which one's own behavior must take place. To take full advantage of the insider's personal understanding of the situation, including what is helpful and harmful, the insider's involvement in assessing it should be sought and encouraged. Furthermore, to maximize potential, the person with CID can well serve as **co-manager** in the rehabilitation process whenever feasible.

Another significant perspective is provided by the **Coping vs. Succumbing Frameworks.** These two frameworks orient the person in opposite directions. In considering their essential differences presented below, bear in mind that whenever "the person" is referred to, it is the person who is perceiving the situation, that is, oneself or an outsider, such as a professional, stranger, friend, and so on as the case may be.

The significance of the two contrasting frameworks may best be clarified by highlighting the striking *qualitative differences* regarding their positive and negative emphases. The succumbing focus is on the difficulties and heartbreak of the condition, not on the challenge of meaningful adaptation and change. Attention is placed on what the person cannot do, on what the person cannot enjoy. The condition is seen as central, overriding everything else about the person. *The person as an individual, with a highly unique personality, is lost.*

The coping framework, on the other hand, represents a constructive view of life with CID. It orients the perceiver to appreciate the person (self or other) as having abilities of *intrinsic value*. People with CID are regarded as *active participants* in their own lives and community, not as devastated, passive victims. Managing difficulties has a double focus. One focus is on *environmental change* – that is, changing those alterable conditions that add to the person's limitations, such as architectural barriers, lack of employment opportunities, discriminatory practices, family problems, and inadequate health care, education, housing and transportation. The second focus is directed toward *change in the person* through medical, psychological, and other health-care approaches, through education and training that lead to new skills, and through *value changes* that reinforce self-respect.

With regard to the suffering connected to some aspects of disability, the coping framework is oriented toward seeking solutions and discovering satisfaction in living. It recognizes the illness or disability as only one aspect of a multi-faceted life that includes abilities as well as disabilities, gratifications as well as frustration. To move toward accomplishing these diverse and ideal goals obviously requires the work of many people over time. Note that the coping framework applies not only to the person with a CID, but also to the outsider, including the wider society, in helping to improve the situation.

Keeping in mind the significance of the main qualitative differences between the two frameworks, we can briefly summarize the essence of the coping framework in the following statement: *What is at stake is replacing the negative cognitive-affective focus by consciously deciding to discover those resources in both the person and the environment that need to be accessed to cope effectively with the negative barriers of the total situation.*

We need to be aware, however, that not all coping efforts can be regarded as positive. For example, consider the case of coping with stigma that ends up in social withdrawal and unnecessary isolation. We also need to be aware that there are times when it is better for the person experiencing an illness or disability to temporarily withhold the coping framework by acknowledging the frustration and suffering, rather than to dismiss these feelings in pursuing change and adaptation. Furthermore, we need to realize that coping is not a uniform process. There may be down times when the person is unmotivated, needs "time out," or even is in despair, having succumbed to the negatives. With the sensitive support of others, however, time is on the side of the person who generally rallies to become re-engaged in the coping process. As for professionals, because the negative flaws of human perception are so powerful, it is incumbent to deliberately search for and marshal those constructive forces in the person and resources in the environment that can energize this progress.

Finally, there is the crucial role played by **Values** undergirding theory, research, and clinical approaches. For example, it makes a difference if the professional values the *uniqueness* of the individual and situation in order to avoid a generic approach, and instead, takes into account the special needs of the person and the particular issues in the social and physical environment. It makes a difference if the professional believes that the active participation of the person in the planning and execution of the rehabilitation program is to be sought as fully as possible. It behooves professionals to self-monitor their efforts in order to detect possible violations of their own values. Twenty elaborated value-laden beliefs and principles are available, for the reader to review, in the preface of Wright (1983).

In conclusion, sensitization to the pitfalls of flawed human perception allows the professional to shift to a viable coping approach. The goals, to reduce limitations and suffering and to improve the quality of life of the individual, are best served by drawing upon the insider's perspective and active participation, with the support of underlying values. Keeping the caveats in mind, the reader will be in a better position to separate the wheat from the chaff in harvesting a rich store of ideas for theory, research, and clinical applications that will enable people to live constructively with CID.

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| **Coping** | **Succumbing** |
|---|---|
| 1. The emphasis is on what the person *can do.* | 1. The emphasis is on what a person *cannot do.* |
| 2. Areas of life in which the person can participate are seen as worthwhile. | 2. Little weight is given to the areas of life in which the person can participate. |
| 3. The person is perceived as playing an *active role* in molding his or her life constructively. | 3. The person in seen as *passive,* as a victim of *misfortune.* |
| 4. The accomplishments of the person are appreciated in terms of their benefits to the person and others (asset evaluation), and not evaluated because they fall short of some irrelevant standard. | 4. The person's accomplishments are minimized by highlighting their shortcomings (comparative–status evaluation, usually measured in terms of "normal" standards). |
| 5. The negative aspects of the person's life, such as the pain that is suffered or difficulties that exist, are felt to be manageable. They are limited because satisfactory aspects of the person's life are recognized. | 5. The negative aspects of a person's life, such as the pain that is suffered or difficulties that exist, are kept in the forefront of attention. They are emphasized and exaggerated and even seen to usurp all of life (spread). |
| 6. Managing difficulties mean reducing limitations route changes in the social and physical environment as well as in the person. Examples are:<br>a. eliminating barriers<br>b. environmental accommodations<br>c. medical procedures<br>d. prostheses and other assistive devices<br>e. learning new skills | 6. Prevention and cure are the only valid solutions to the problem of disability. |
| 7. Managing difficulties also means *living on satisfactory terms* with one's limitations (although the disability may be regarded as a nuisance and sometimes a burden). This involves an important *value changes.* | 7. The only way to live with the disability is to resign oneself or to act as if the disability does not exist. |
| 8. The fact that individuals with disabilities can live meaningful lives is indicated by their participation in valued activities and by their sharing in the satisfaction of living. | 8. The person with a disability is pitied and his or her life essentially devaluated. |

# Preface

> Far from a digression in the stream of existence, trauma intensified existence, bringing forth elements of experience too easily clouded over by the seductive predictability of day-to-day, so-called "normal" life. From the beginning, disability taught that life could be reinvented.
>
> John Hockenberry (1995, p. 79)

The purpose of this book is to study human coping following the onset of, and the ongoing stressor of, a chronic illness or disability (CID). Theories and empirical studies about coping will be examined about individuals who have faced the challenge of CID and who have coped with CID in different ways. It is hoped that the multifaceted aspects of this book will spark new research and clinical work, which in turn, may encourage individuals with CID to explore better ways of coping and of appreciating the time-limited phenomenon called life.

## Stress Related to Chronic Illness and Disability

Most people consider the *onset* of a CID as a *negative* event (e.g., for some, it is a time of psychological "darkness"). This is evident not only by individuals' reactions (e.g., anxiety, anger, depression) when a CID occurs, but also by the reactions (e.g., frustration, anxiety, confusion, avoidance) of family members and friends. Even if an individual with a CID has accepted the bodily or mental changes, and family and friends have become accustomed to these changes, psychological reverberations of the CID can still be experienced in a person's social environment (i.e., employment, leisure, or other public settings), due to strangers' reactions of fear, curiosity, avoidance, prejudice, or other types of stereotypical perceptions and discriminatory practices. Social attitudes toward people with CID often have negative undertones and, as a consequence, may cause additional stress for the individual with CID.

The view that the onset of CID is a *negative occurrence* (i.e., a distressing event) is ubiquitous: Who would hold celebratory parties or congratulate someone after it happened? Yet, ironically, sometimes the diagnosis of a CID can literally *save* a person's life, if followed by appropriate treatment (e.g., the diagnosis of insulin-dependent diabetes or cancer). Further, sometimes a CID is a consequence of a sudden event (e.g., loss of a limb due to stepping on a mine, paralysis from a severe motor vehicle accident) that could have resulted in a much more serious outcome, including death. Despite experiencing "lesser trauma" than what could have occurred, it may be difficult for individuals with CID (or their family and friends) to appreciate the fact that *one is still alive,* especially when life following some CID is so different from the life that was anticipated or imagined, and when that life requires alterations in personal habits, modes of functioning, and even self-perceptions. The affected individual may dwell on the perceived tragedy of the CID, instead of emphasizing existing and new potentials that ensue from continued life, though radically altered, or focusing on the abilities that were preserved and the possibilities that still remain.

## The Battle with Oneself

Living with CID is often challenging. Some people, such as those who have active disease-processes, may feel as if their bodies or minds are a war-zone on a microcosmic level (e.g., neurobiological levels that fluctuate dangerously outside of normal levels, viruses or cancers that wage war against one's own body and the immune system). Daily living may be a focus on a life-or-death survival within one's own microcosm, and thus may be perceived as dangerous, uncontrollable, and unpredictable. Life can take on a different kind of meaning and value when a person fights daily to live, or when they have come close to death. The existential awareness of life and death can lead to heightened appreciation of life, relationships, and what is still possible.

In cultures that emphasize physical strength, beauty, self-control, and certain ideals and idolizations of "perfection," individuals with a CID may battle with themselves and their conditions, bodies, or minds, and their lack of control in certain areas. They may battle feelings of anger and self-hatred, because they resent their appearance and physical or mental functioning, or because their expectations about their own ability to lead "normal" lives do not match the reality they experience. So how can people with CID learn to successfully cope with their CID? How do they find successful ways of managing their changed or changing selves, and their often oppressive physical and social environments?

## The Battle with Environmental Influences

Because of their conditions, individuals with CID may encounter a wide range of responses from the environment, some negatively tainted (e.g., stigmatization, discrimination) and some positive (e.g., compassion, needed assistance). The reactions from the social environment may create a negative feedback loop, in which societal negative attitudes toward people with CID may feed into one's own battling with the perceived negative experience of CID. Similarly, because of these attitudinal and physical barriers, individuals with CID may experience all sorts of continuous environmental battles (e.g., on architectural, attitudinal, and financial levels).

Family, friends, or acquaintances may provide a balance to negative environmental influences by their positive messages and empathic support. Because CID often involves a long, if not life-long, journey, which will require a wide range of coping strategies for numerous life challenges, the question, "How can I help you cope?" may be an effective expression of support to an individual with a newly-acquired CID. Such a question permits an individual with CID to state if help is indeed required and what kind of help is needed, and also sends the implicit message that the person has the ability to cope (with or without support). It also allows people in the individual's social network to assuage CID-related feelings of anxiety and helplessness, and to replace those feelings with tangible, active measures that are in harmony with the wishes of the person with CID.

## Coping with CID

Coping can take many forms. It may be growth-oriented (e.g., problem-solving of issues impeding one's functioning, thinking positively about the possibilities available in the future) or negatively weighted (e.g., avoiding certain situations, catastrophizing), or it can encompass both forms simultaneously. Some coping strategies can help individuals restore a holistic equilibrium, while others can cause them to spiral into stressful and dissatisfying lives.

Despite the sometimes enormous challenges created by CID, many people have reported the development, over time, of positive perspectives and experiences in their lives (e.g., a greater appreciation for life, relationships, their own strengths; newly found meanings in life). Even with positive personal views and supportive physical, social, and emotional environments, CID can still be a constant hassle. How can people learn to minimize the ever-present ramifications of a CID, to view their conditions as only one component of multiple aspects of their lives, and to integrate the CID into their daily lives, as one of many challenges?

The theories and research that are examined in this book will hopefully help answer some of the aforementioned questions. Coping strategies may offer a means by which the impact of a CID is minimized, and may help a person arrive at the psychological place in which the undeniable presence of a CID no longer dominates the person's mental and emotional landscapes, but becomes a part of an individual's cognitive-affective background, permitting positively-valenced perceptions, thoughts, feelings, and activities to take primary importance.

## Contents of the Book

This book focuses on understanding the multifaceted processes of how people struggle and cope with the irreversible presence of CID in their lives. Although every individual will experience a unique mixture of life events, processes, outcomes, and successes in their coping with CID, this book surveys trends that clinicians and researchers have observed. This book also examines empirical findings, because patterns noted among individuals with specific types of CID may provide clinicians with valuable information on those coping styles and strategies, which may help to alter or bolster one's coping with CID-generated, stressful life-events.

This book contains two parts. Part I discusses a range of theoretical and conceptual perspectives on coping, including selected applications of coping with CID. Part II contains chapters that focus on coping with 12 specific types of CID. Most of the chapters in Part II follow a rather standardized format, although this format is applied flexibly, in view of the expansive research in specific areas (e.g., newly developed therapeutic modalities, randomized clinical intervention studies). The format of the Part II chapters includes the following components: Etiology and description of the CID, typical medical regimens, the empirical literature on coping with the specific CID, physical and psychosocial/ behavioral interventions, and finally, when applicable, vocational and social implications of the CID.

## A Note about CID and Employment

Some chapters include discussions about vocational rehabilitation. This topic is included, because employment may be one of the most effective means of social integration for individuals with disabilities. Employment not only provides financial independence, but it often provides needed health insurance, a regained meaning in life, personal independence, a place to learn new skills, and social interaction with a diverse group of people. Thus, sections on employment-related issues are included in several of the chapters of this book, as adaptive coping often increases vocational functioning and successful integration into the community.

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